

**St. John's National Academy of Health Sciences**

**Bangalore - 560034, India**



# **UNIT OF HOPE**



**Hope for children with disability**

CLIC SOCHARA IS104



For CLIC In 19/8/13

## THE UNIT OF HOPE

### Summary

The Unit of Hope was inaugurated on 18<sup>th</sup> August 2004 as a felt need. This was initiated by a group of committed doctors who felt the need to provide a comprehensive multidisciplinary care for children with special needs and was supported by the management. Comprehensive care refers to complete care which involves health, education, empowerment and social aspects of care and support to be given to the individual and family so as to optimize the potential of the child with special needs.

This venture was initiated by the orthopedic department along with pediatric and community health departments and was ably supported by all other departments involved in the care of children with disabilities.

In the last 8 years since its inception, the unit has taken care of nearly 2500 children in the clinic and has evaluated many more children through various outreach programs. Having proven that it is possible for a group of interested doctors to initiate and sustain the functioning of a multidisciplinary service, the initiative was expanded to achieve further objectives.

### Aim

To establish a sustainable comprehensive, multidisciplinary referral center and community based programme for the prevention, early detection and management of children with special needs by enhancing their potential and equipping them to lead a productive life.

### Objectives

1. To establish the “Unit of Hope” center /unit in St. John’s Medical College and Hospital.
2. To establish the “Unit of Hope” community outreach facility and programme.
3. To establish early detection programme and prevention strategies so as to reduce the incidence and severity of disability.
4. To develop the Unit of Hope into a regional training centre for training medical, paramedical and community based workers in the comprehensive multidisciplinary or integrated approach in the management of children with special needs.
5. To conduct research to enable us to improve care of children with special needs
6. To evaluate the programme on a periodic basis to ensure that objectives are being fulfilled

One of the objectives when this concept was initiated was to establish a sustainable, well equipped, comprehensive, multi disciplinary referral and training centre. The term multidisciplinary refers to evaluation of a child by all concerned specialties but at a single point or place of interaction. The term comprehensive refers to care and support for health, education, vocation, empowerment and social adaptation with the intention of optimizing the child's potential.

To achieve this it was essential to have a separate area where these children with special needs could be evaluated – hence the building plan was thought of. With support from CBM and approval and support of the management funds were generated for the building. Currently the

ground floor has been furnished and is being utilized and the second floor is in process of being furnished. A therapy center at the outreach center in Mugalur has also been established.

CBM (Christoffel Blinden Mission) supported us and their sustained support to us is expected in this venture. The model of Unit of Hope in SJMCH was chosen by CBM, Germany from among 160 other programs that they support and was showcased by them at the recently held International Conference for Prevention of Blindness.

In terms of the institution, this initiative will be considered as one of the unique programs of SJMCH which will distinguish us from other teaching institutions in the country. This is in keeping with our institutional objectives of serving the underprivileged and vulnerable masses. It will also provide a unique opportunity for our students to be sensitized to children with special needs.

The commitment of the existing group has enabled successful team functioning and patient care. The venture is expected to attract as well as generate funds. The long term plan is to progress to a regional training centre to train all levels of health care personnel. Therefore funds will not only be generated by service but also by training and research.

The future plans for Unit of Hope includes expansion of outreach centres, provision of facilities beyond medical care for children with special needs, formulation of training programs in all aspects of care for children with special needs and research to enable better care of these children. It is also proposed to establish a parent support group to help in addressing the issues of parents and care givers. In view of achieving this goal, parent training programs have been initiated but there is need for further work in the area.

## OUR VISION FOR THE UNIT OF HOPE

### Service

- To improve outpatient services- a disability-friendly hospital working on all days of the week
- To ensure that all departments may function from a single building equipped with required instruments, assessment and training protocols and facilities for multidisciplinary care



- To continue to provide subsidized care for those who cannot afford
- To strengthen community/ outreach program – establish basic units in the community
- To extend screening and early intervention programs to larger areas in the community

## Training

- To establish training programs related to children with special needs for all levels of health care personnel
- To establish health education and awareness programs for parents, patients and NGOs.



## Research

- To initiate and conduct research to prevent disability, to decrease severity of disability and provide affordable effective therapy/ rehabilitation as a part of the process of providing care for these special children.

The long term plan is to establish a regional training and service centre for children with disabilities. This entails strengthening the Unit of Hope to form a well established, well equipped, referral centre for children with any type of physical or intellectual disability and also incorporate components of training and research. We also hope to create multiple small basic units at the community level with a link to the referral centre

## CURRENT STATUS

The Unit of Hope has about 2500 children registered in its clinic, has a well established clinic at Mugalur, has conducted several outreach camps in places like Gudalur (Tamil Nadu), Doddaballapur, Palamner, Miraj-Sangli, has provided surgical/ rehabilitative treatment for many of its patients and has initiated a few early intervention and early detection programs.

A special fund has been created to provide subsidized care for those who cannot afford.

The Unit of Hope team consists of professionals from Departments of Paediatrics, Orthopaedics, Physical medicine and Rehabilitation, Physiotherapy, Occupational therapy, ENT, Audiology and Speech Pathology, Ophthalmology, Child and Adolescent Psychiatry and Psychology, Community Medicine, Medico-social work and Special Education.

Part of this team (Paediatrics, Orthopaedics, PMR, Physiotherapy and Special education) has begun functioning in the Unit of Hope building since June 5<sup>th</sup>, 2013. Therapy services are

functional on all days of the week. Multidisciplinary clinic is presently functioning on every Wednesday and Friday. On Tuesdays and Thursdays, the high risk neonatal follow up clinic has been functioning since 1<sup>st</sup> July, 2013.



#### **List of doctors working for the unit of hope:**

Department	Name of Faculty	Department	Name of Faculty
Orthopaedics	Dr. Saji Joseph Dr. Ramesh L.J. Dr. Binu Kurian Dr. Mahadev	ENT	Dr. Ramesh A.
Paediatrics	Dr. Swarna Rekha - coordinator Dr. Maria Lewin	Audiology and Speech pathology	Ms. Nagapoornima Ms. Sowmya Nayak Ms. Amrutha Athul
Community Medicine	Dr. Dominic Misquith Dr. Deepthi Shanbhag	Ophthalmology	Dr. Suneetha N. Dr. Usha Vasu
Medico-social work	Ms. Rathna Kumari	Child Psychiatry and Psychology	Dr. Ashok Mysore Dr. Vijaya Raman
PMR	Dr. Kurian Zachariah Dr. Rajalakshmi Hariharan	Special Education	Dr. Shilpa K.S.
Physiotherapy	Ms. Akshata Nadgir	Occupational therapy	Ms. Seema Kumari

#### **Day to day functioning**

The multidisciplinary clinic functions on Wednesdays and Fridays. The high risk Neonatal Follow up Clinic (NFC) functions on Tuesdays and Thursdays. Therapy and special education services are available on all days. The expected plan is for all units to function on all days



	Current	Future
Paediatrics, Orthopaedics, PMR*	Wednesday, Friday	All days
NFC*	Tuesday, Thursday	
ENT	Tuesday, Wednesday, Thursday	All days
Ophthalmology	Wednesday	All days
Psychiatry	Wednesday, Saturday	All days
Psychology	Wednesday, Thursday	All days
Medico-Social work*	Wednesday	All days
Special education*	All days	All days
Occupation therapy*	All days	All days
Physiotherapy*	All days	All days
Speech and hearing	All days	All days
Low vision		All days
Specialty clinics		Once a week

Clinics functioning in new building have been marked with \*

#### **TYPES OF SERVICES PROVIDED:**

##### **1. Out-patient services**

1. Orthopedics
2. ENT
3. Pediatrics
4. PMR
5. Child Psychology and Psychiatry

6. Ophthalmology
7. Special education
8. Neonatal Follow up clinic
9. Medico-social work

## 2. Inpatient services

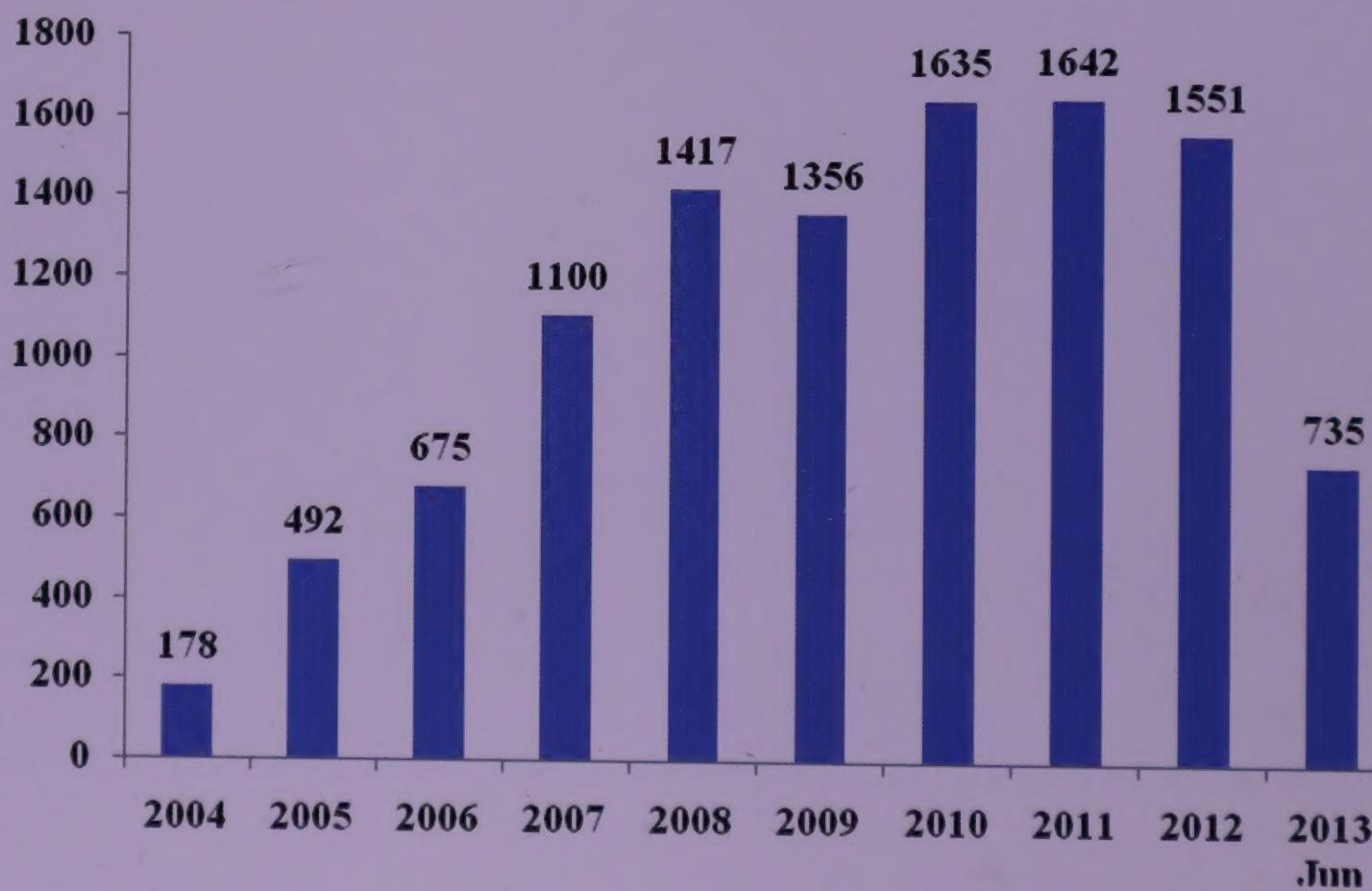
1. Orthopaedic ward- surgical treatment- Doctors, physiotherapists and occupational therapists from the United Kingdom visit once a year.
2. Pediatric ward- Evaluation and treatment
3. PMR- Evaluation and treatment
4. Ophthalmology and ENT – treatment

## 3. Early intervention

- Metabolic screening
- Universal hearing screening
- High risk ROP screening
- Early intervention in NICU
- Early intervention during follow up

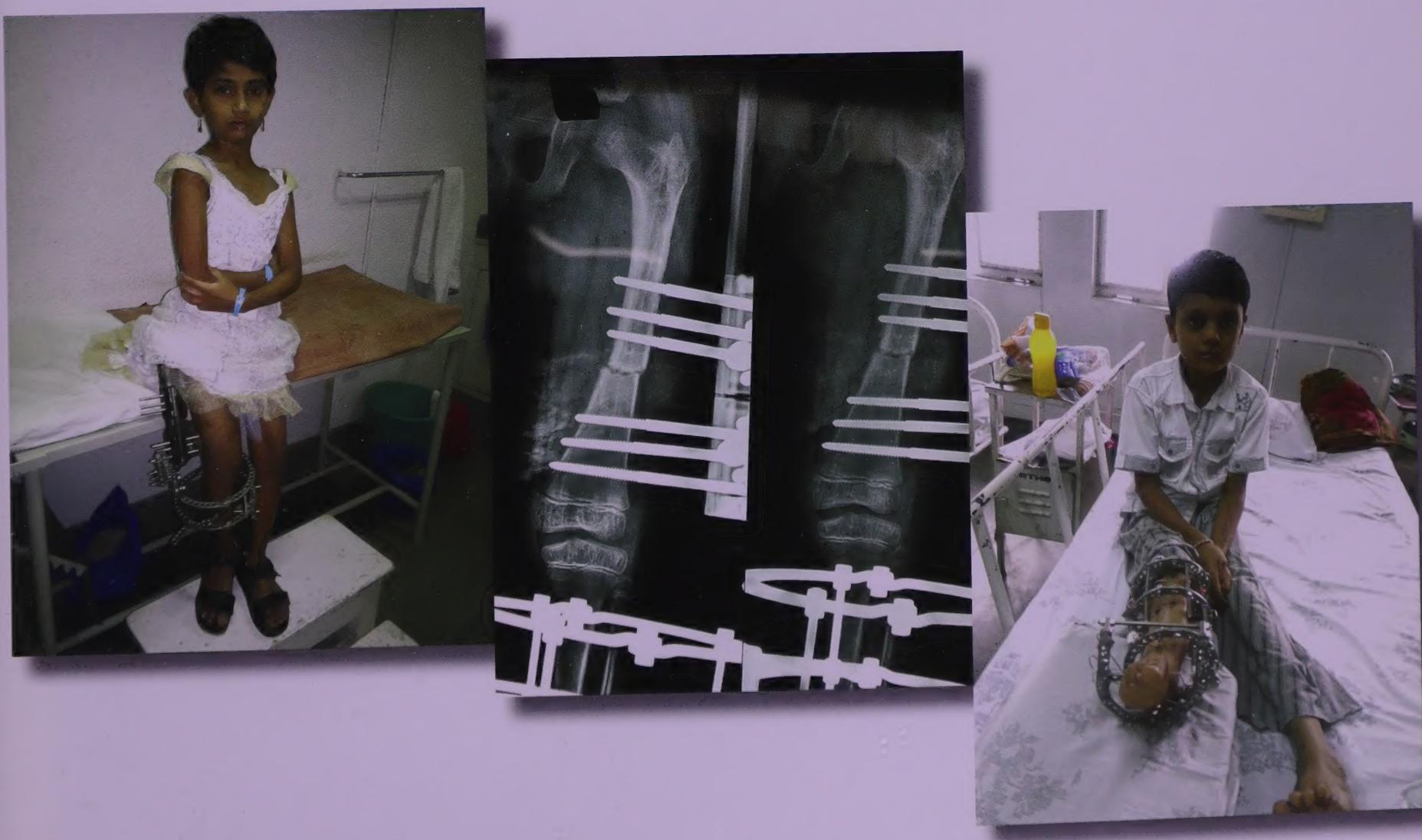
## STATISTICS:

### Number of patients per year



**Statistics from 26.8.2004 to 5.8.2013**

Sl. No.	Date	Number of surgeries
1	28.8.04 - 31.12.04	28
2	1.1.05 - 31.12.05	69
3	1.1.06 - 31.12.06	51
4	1.1.07 - 31.12.07	51
5	1.1.08 - 31.12.08	59
6	1.1.09 - 31.12.09	70
7	1.1.10 - 31.12.10	102
8	1.1.11 - 31.12.11	66
9	1.1.12 - 31.12.12	91
10	1.1.13 - till date	95
Total		683



## Statistics for the last 2 months (June-July, 2013)

Sl. No.	Clinic	No. of patients seen
1	Unit of Hope consultation (Multidisciplinary)	300
2	Physiotherapy	250
3	Special education	80
4	Neonatal follow up clinic	120 (July)

The type of patients seen in the unit of hope could vary from a simple case of CTEV - congenital talipes equino varus to a multifunctional problem like cerebral palsy. Children may have functional disability of one system such as hearing impairment or can have more than one disability. Children registered in the Unit of Hope are seen by all consultants and treatment is offered in the form medical therapy, nutrition, physiotherapy, occupational therapy, speech therapy, cognitive stimulation, behavioural management, counseling or surgery. In addition funds have been raised to enable us to provide concessional care to the needy.

### Services for early assessment for disability

In addition to curative services a lot of emphasis is placed on the early detection and preventive aspects. These services include early detection of hearing impairment through universal hearing screening, screening for retinopathy of prematurity- a condition which can cause blindness if untreated, screening for autism, ADHD etc.

1. Retinopathy of prematurity- Screening all high risk neonates are screened for retinopathy of prematurity at 2 weeks of age and at 2 to 4 weekly intervals
2. Universal hearing programme- all neonates born in the hospital including high risk neonates are screened for hearing by Oto-Acoustic Emission at 6 weeks of age and repeated if needed. Over the last 4 years nearly 1000 neonates have been screened for hearing impairment using OAE, behavioural audiology and BERA
3. Neonatal follow-up clinic- all high risk neonates are evaluated in the neonatal follow up clinic for any disability and occupational therapy is given to these high risk neonates in the intensive care unit and in the follow up clinic



### Outreach programmes:

The community component is an integral part of the program. The issues in the community include detection, education and rehabilitation of these children. The stigma of disability is a

huge problem particularly in the community that needs to be addressed by patient / parent education

**A) Medical Camps have been conducted at the following centres**

i) At the **Centre for Social Action Trust at Palamner**: In these visits disabled children of destitute and tribal areas around Palamner District of Andhra Pradesh were screened.

Sl. No.	Date	Number of children seen
1	11.9.2004	158
2	14.10.2006	218
3	10.8.2012	152

ii) In **Tumkur district** on 19<sup>th</sup> March 2005. 216 disabled children were screened. These screened children are being treated at this unit at St. John's Medical College Hospital in a staged manner.

iii) At **Pilar Health centre, Andaman and Nicobar Island** in April 2008.

Screened about 400 children over a period of one week,

- 14 surgeries performed

iv) At **Adivasi Hospital in Gudalur, Tamilnadu**

- Started from June 2008.
- Visits by Orthopaedicians every 2 months (ongoing ...)

Number of patients seen	4280
Number of children operated	180

v) At **Sangli Mission, Maharashtra**. Teams from Orthopedics, Pediatrics and PMR have visited this place 6 times since the last 3 years. Patients from here are brought to SJMCH for surgery.

Number of children seen	1000
Number of children operated	120



vi) Camp at Doddaballapur- Conducted in November, 2011

B) Every third Friday of the month Unit of Hope clinic has been conducted at the Community Health Training Centre, Mugalur, Sarjapur taluk, run by Department of Community Medicine starting from May 2006.

## TRAINING

### *Neonatal resuscitation programme ( NRP )*

This course basically consists of identification, resuscitation of high risk new-born to prevent mortality, morbidity and disability due to intra-natal and peri-natal causes.

NRP programs are held once a year for all interns, once a year for all post graduates and at least once a year for Nurses. In addition we conduct these programs for other health care personnel within and outside institution.

### *CME programs*

Under the UOH we have had 2 CME programs on cerebral palsy. The recent one CONCEPT (Conference on Childhood Neurodisabilities and Cerebral Palsy- 2012) was a 2 day Conference with participation of eminent professionals from national and international fora.

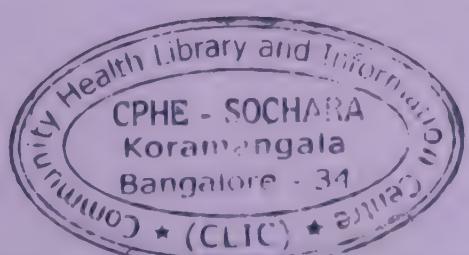


## Parents' Training Workshop

Dr. Shilpa and Mrs. Rathna Kumari have been conducting training programs for parents of children with special needs since February 2012. So far 5 programs have been conducted and the response from the parents has been promising.

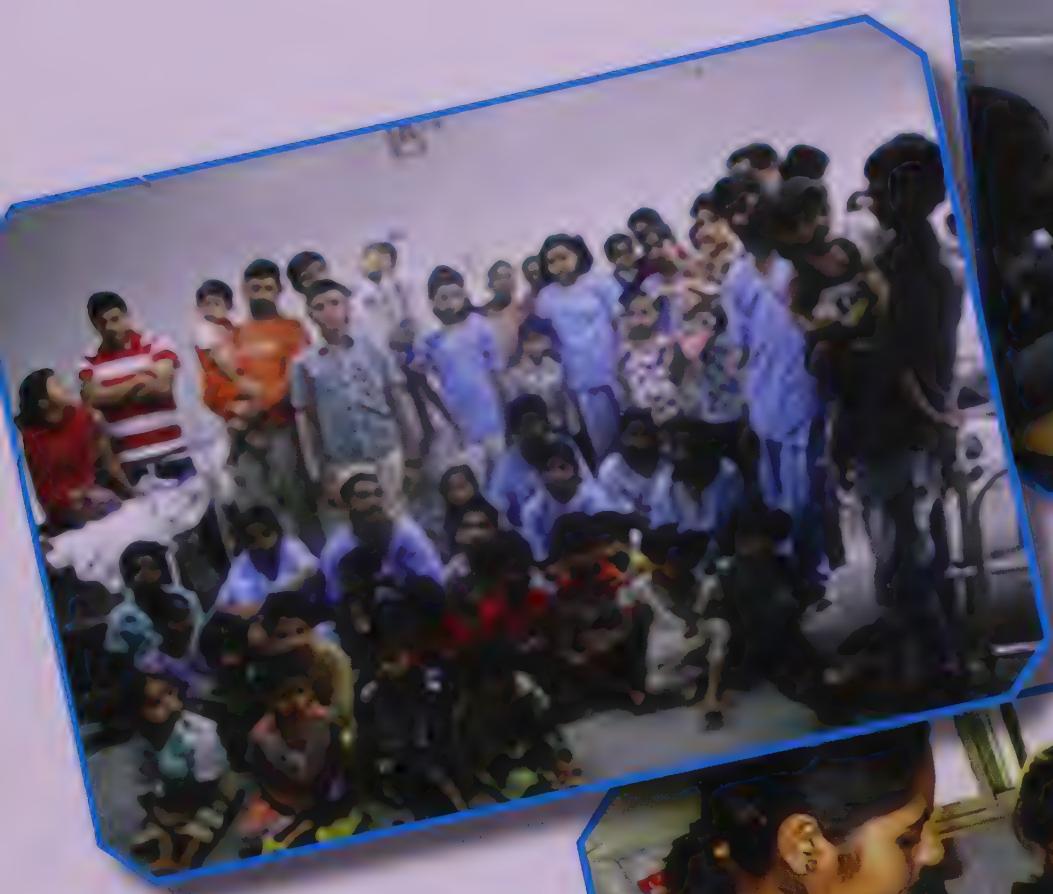
Sl. No.	Date	Number of patients seen
1	1.2.2012	22
2	27.6.2012	8
3	17.10.2012	12
4	9.1.2013	10
5	31.7.2013	6

It is important to educate and train more health care personnel in various aspects of care of children with disability. We hope to establish multiple training programs to all levels of health care personnel and establish an excellent patient education and parent support group. The unique feature of this would be that parents would be forming this group.

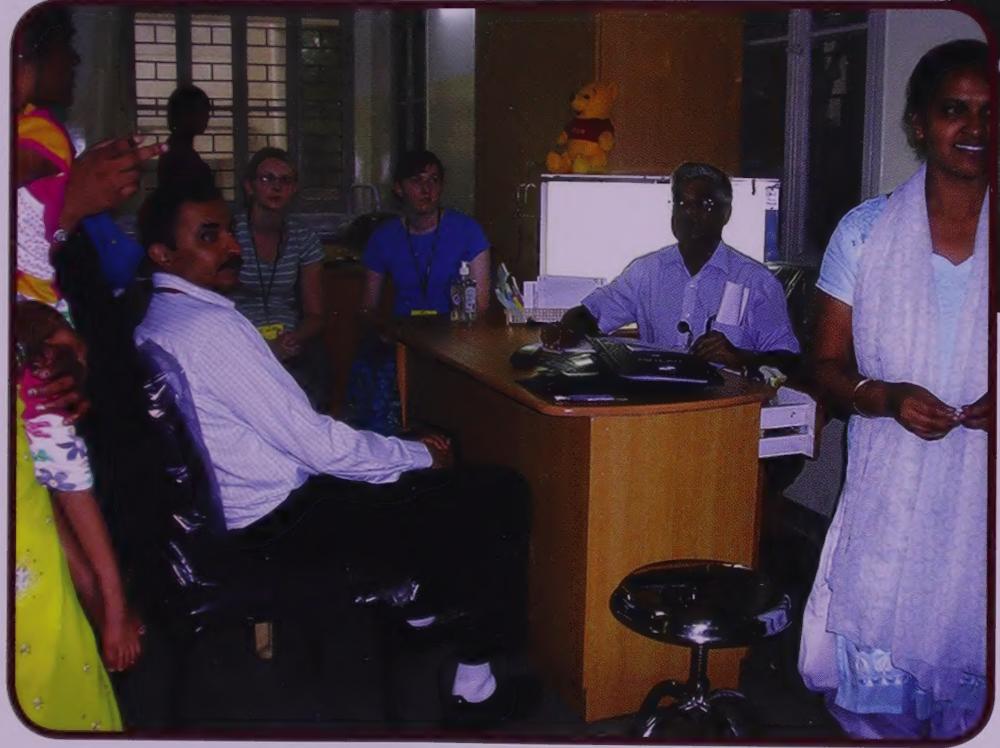
















The design above is inspired by Worli art form and represents the Unit of Hope which is a multidisciplinary team of professionals from various disciplines who work for children with disabilities at St. John's Medical College Hospital, Bangalore, India.

The identical strips above and below show children who are running, lying down, crawling and jumping.

The main strip in the middle shows the following departments from left to right:

Paediatrics- examining the child on the examination table; describing nutrition advice

Orthopaedics- conducting surgery in the operation theatre, application of lower limb cast

Physical Medicine and Rehabilitation- therapist doing physiotherapy and occupational therapy exercises

Ophthalmology- retinal examination; providing glasses to the child

ENT- examining the ear; conducting speech therapy session

Child Guidance Clinic- family counseling; block design arrangement as a part of IQ assessment

Community Health- house to house survey- community based rehabilitation

Medico-social work- conducting parental training and meetings

Special education- early intervention sessions- dance and music therapy, ball games

## UNIT OF HOPE

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